# A Qualitative Assessment of Prenatal Care and Prenatal Care Access in Louisville / Jefferson County

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## **Executive Summary**

We conducted 11 focus groups and seven qualitative semi-structured interviews with 34 recent parents (those who had given birth within the past three years) who had received prenatal care and/or given birth in Louisville / Jefferson County. Throughout this report we will use "Louisville" to refer to the Louisville / Jefferson County area and parents who have utilized or are connected to prenatal and pregnancy care therein. The study's objective was to understand better the perspective of prenatal and pregnancy care experiences from mothers who are less likely to access prenatal care, or otherwise face barriers to accessing prenatal care, specifically Black and immigrant/refugee mothers, and mothers who have experienced substance use disorder in Louisville.

Pregnancies and birth were life-changing for all the parents that we interviewed. Most parents reported positive experiences with prenatal care, and parents who had positive experiences trusted providers, felt heard, and felt well taken care of by their providers.

Still, prenatal care could be improved, as parents sometimes reported traumatic prenatal, pregnancy, and delivery experiences.

- Some parents reported that accessing prenatal care or knowing where to go was troublesome. This may be particularly true for parents who are recent immigrants or refugees or who have newly come to Louisville.
- Cost and insurance coverage prevented some parents from receiving the types of care that they desired.
- Disruptions in care and miscommunications were common across reports, which may be due in part to providers being overwhelmed or overloaded.
- Black mothers reported that they experienced medical racism from providers particularly close to or at the time of delivery or when they requested treatment for pain.
- Parents felt like they had to be their own advocates, highlighting that those parents may be unable to do so at various points of pregnancy and the absence of or lack of available advocates who have parents' wishes in mind during pregnancy and delivery.
- Parents who gave birth before the COVID-19 pandemic reported feelings of isolation, but the pandemic may have made these feelings more severe.

Parents also discussed aspects they valued from the care they received and elements of care that they wished that they had experienced.

- Parents valued building trusting relationships and rapport with providers. Parents wanted to know the people who provided pregnancy care, including at the time of delivery. They wanted to be sure that these providers valued parents' birth plans and interests.
- Positive experiences with prenatal care often coincided with feeling heard by their providers and having their concerns taken seriously.
- Black parents expressed a desire to see more Black women and nurse-midwives responsible for pregnancy and prenatal care, and parents who worked with them frequently reported positive experiences as a result. In addition, parents believed that

these providers would provide care that was more responsive to their needs and desires and more culturally competent.

We asked questions specifically about non-medical forms of prenatal care and support that parents found valuable or wish they had access to during their pregnancies.

- Some Black parents expressed a desire to access birthing options such as Commission for the Accreditation of Birth Centers¹ (CABC) accredited birthing centers, births outside of the hospital, vaginal birth after caesarean (VBAC), unmedicated births, water births, and models of care such as midwifery. In some cases, parents actively tried to seek out these options and were met with financial barriers or a lack of services in the Louisville area.
- Some parents needed or expressed an interest in resources that could help them navigate prenatal and pregnancy care in Louisville. Parents had to do their own research at times which could lead to parents not getting the best information possible. Parents of immigrant origin or new to the Louisville area might have trouble navigating local prenatal and pregnancy care networks.
- Parents expressed a need for advocates such as doulas during prenatal and pregnancy care and at the time of delivery.
- Parents found mentoring relationships with other parents—frequently their mothers, to be valuable, and parents who missed out on these relationships felt their absence.
- Parents reported value and expressed interest in support in group settings such as listening or educational groups.

Several parents reported a local need for mental health services and improved breastfeeding support following delivery. Some parents wanted to see improved access to counseling services for parents who had experienced postpartum depression and traumatic experiences with labor and delivery. These themes emerged organically in interviews and focus groups even though these were not our primary research focus areas.

## Based on the study's findings, the following policy and practice directives emerged as recommendations:

1. Ensure providers work with and respond to parents and mothers to ensure that they feel heard

Advocates and providers in Louisville's prenatal and pregnancy care spaces need to focus on ensuring that they create practices that listen to and adhere to parents' concerns and desires in culturally competent and receptive ways.

2. Increase access to caseworkers, doulas, and other advocates for parents during prenatal and pregnancy care

Investments should be prioritized to increase the number of caseworkers and doulas and ensure meaningful access for all birthing parents. These allied professionals can

provide aid and advocacy for expecting parents and increase access by supporting policies and programs that make these resources affordable to parents.

3. Increase support and guidance in group settings

Advocates and supporting organizations connected to Louisville's prenatal and pregnancy care spaces should provide opportunities for support in group settings to help expectant parents connect with a support network.

4. Increase the presence of Black women and Nurse-Midwives in OB spaces

Advocates and providers in Louisville's prenatal and pregnancy care spaces need to focus on expanding the number of practices and providers offering prenatal and pregnancy care services for Louisville's parents. Existing practices should prioritize recruiting and retaining Black women providers, and area hospitals and practices should employ nurse-midwives. In addition, policymakers should consider expanding the ability of nurse-midwives to practice independently or the spaces they can work in.

5. Promote options for births outside of the hospital, vaginal birth after caesarean (VBAC), unmedicated, water births, and models of care such as midwifery.

In Louisville's prenatal and pregnancy care spaces, advocates and providers should focus on expanding access and affordability of birth options such as: births outside of the hospital, VBAC, unmedicated, and models of care such as midwifery. This would address the requests of the Black mothers who reported a strong distrust of medical providers from whom they had experienced racism.

<u>House Bill 268</u><sup>2</sup> is related to establishing and creating standards for free standing birthing centers in Kentucky. Having (increased) access to a CABC accredited birthing center with strong ties to an area hospital would create safe alternatives to hospital births and could cut down on overly burdened providers.

6. Increase support following delivery

Based on these reports, we recommend that providers and advocates ensure that breastfeeding support is available and encouraged. Communication should be clear so that parents who are breastfeeding or desire to breastfeed don't feel undermined by providers. For instance, we heard a report from one mother who was trying to breastfeed who was upset when she found out that neonatal intensive care unit staff were feeding her baby Similac bottles.

We also recommend that advocates and policymakers make counseling resources related to postpartum depression affordable and accessible to the mothers who need them. Area hospitals should standardize the use of evidence-based mental health screenings. Standardizing such a practice could help providers to initiate conversations with new parents about postpartum depression as well as postpartum-related assistance and care. Area hospitals and referring agencies should also strengthen knowledge of, and connections to culturally concordant or sensitive mental health providers in the Louisville area, so that they can make such referrals when evidence-based assessments suggest that postpartum care may be needed.

## Introduction

Prenatal care is an invaluable resource and is vital for preventing adverse birth outcomes such as low birth weight. However, not all parents have equitable access to prenatal and pregnancy care during pregnancies despite its importance for maternal and child health. This research was commissioned by the Ready for K Alliance to understand better the experiences of new parents in Louisville / Jefferson County in accessing prenatal care. The information gathered will be used to inform local and state policymakers, along with policies and practices of OB hospitals and maternal supporting community organizations to best allocate resources and assets to provide greater access to culturally competent prenatal care for all Louisville Metro residents.

In what follows, we outline how this project came to be and was carried out. Second, we highlight research literature and reports on the landscape of prenatal care and prenatal care access with a specific focus on Louisville. Third, we outline how our research study was conducted and its justifications. Fourth, we highlight the themes that emerged from this study. Fifth, we discuss policy and practice directives that can be derived from our findings.

## Background on Prenatal Care

We preface this review of the literature with an important discussion of terms. This section refers to pregnant people as "mothers" or "women" because the data that we use are usually defined by a binary gender choice in vital stats or census data. However, we acknowledge that individuals may become pregnant and identify their gender differently. We recommend future efforts to measure the inequities in birth outcomes and prenatal care be inclusive of the spectrum of gender identities.

Black women and women with lower levels of socioeconomic status have inequitable rates of preterm birth, low birth weight, and maternal and infant mortality rates<sup>3-4-5-6-7-8</sup>. Historically, healthcare systems have tended to blame women—particularly Black women—for these inequities<sup>9-10</sup>, for instance, by attributing the disparity of their increased likelihood of maternal death to personal factors like weight, advanced age, dietary choices, and lack of prenatal care. Instead, however, scholars and activists have argued that attention should be focused on addressing the systemic, structural, and contextual factors that influence the social well-being of these populations<sup>8-9-10-11</sup>.

Participation in prenatal care significantly reduces negative birth outcomes<sup>10-12-13</sup>. According to 2016 United States vital statistics, 77.1% of women initiated prenatal care (PNC) in the first trimester of pregnancy in 2016, 4.6% initiated in the third trimester, 1.6% received no PNC<sup>12</sup>.

However, not all groups are equally likely to access prenatal care early in their pregnancies. For instance, younger mothers are less likely to initiate prenatal care at all or during the first trimester of pregnancies. Women in their 30s were the most likely age group to start prenatal care in the first trimester (82.1% of mothers age 30 – 34, 81.7% of mothers age 35 to 39). Mothers under 20 were the least likely to receive prenatal care during their first trimester (61.2% of mothers under age 20 and 36.7% of mothers under age 15)<sup>12</sup>. There are also differences in prenatal care access between mothers who have children for the first time and mothers who have previously been pregnant. For instance, 79% of first-time mothers access PNC in the first trimester compared to 80.1% of second-time mothers, 75.8% of third-time mothers, and 66.2% of the fourth time or more mothers<sup>12</sup>.

Non-Hispanic White mothers are more likely than non-Hispanic Black and Hispanic mothers to access prenatal care early in pregnancies and less likely to receive late or no prenatal care at all. Late prenatal care is defined as not care that is started in the third trimester 12. 82.3% of non-Hispanic White mothers initiated prenatal care during their first trimester compared to 66.6% of Non-Hispanic Black mothers and 72% of Hispanic mothers. Similar gaps in care exist at the local level in Jefferson County<sup>3</sup>. Only 4.3% of non-Hispanic White mothers received late or no care during their pregnancies compared to 10% of non-Hispanic Black mothers and 7.7% of Hispanic mothers 12. Here, this report uses the term "Hispanic" to refer to individuals who trace their roots to Mexico, Puerto Rico, Cuba, Central America, and South America. There are a variety of ways these individuals may choose to identify their ethnic origins, with the term "Hispanic" being the most common and typically used by the U.S. Census Bureau and other governmental agencies that report data about the population. We recognize that this population

of individuals is extremely diverse and have many ways of identifying themselves, their country of origin, and their ethnic identities.

Mothers with higher levels of education are more likely to access prenatal care early and are less likely than mothers with lower levels of education to receive late or no prenatal care at all than mothers with lower levels of education. For example, 87% of mothers who have attained a bachelor's degree or higher received prenatal care during their first trimester compared to 80.2% of mothers who received some college, 73.4% of mothers who completed high school, and 62.7% of mothers with less than a high school equivalency. Similarly, only 3.3% of mothers who have attained a bachelor's degree or higher receive late or no prenatal care at all compared to 4.7% of mothers who received some college, 7.2% of mothers who completed high school, and 11.2% of mothers with less than a high school equivalency. Notably, mothers with higher levels of education may have greater access to jobs that afford them resources or benefits that make it easier for them to access care earlier in their pregnancies<sup>12</sup>.

Mothers using specific methods of payment are also more likely to access prenatal care early and less likely to receive late or no prenatal care at all than parents using other types. For instance, 87% of mothers using private insurance to pay for delivery received prenatal care in the first trimester, compared to 68.1% of mothers using Medicaid, 54.8% of mothers using self-pay, and 75% of mothers using other forms of coverage. Others include Indian Health Service, CHAPUS (Civilian Health and Medical Program of the Uniformed Services) or TRICARE, other government (federal, state, or local, and charity). Similarly, only 2.7% of mothers using private insurance receive late or no prenatal care at all compared to 8.6% of mothers using Medicaid, 19.8% of mothers using self-pay, and 8.2% of mothers using other forms of coverage<sup>12</sup>.

Some of the reasons that mothers hesitate to access prenatal care or forgo it completely could be related to perceived racial discrimination, dissatisfaction with patient-provider communication, lack of treatment adherence, lack of access to health care, lack of transportation, and lack of support.

Even when mothers do receive prenatal care, studies have found significant inequities in how some groups of mothers experience care compared to others. For instance, in an analysis of data from the Listening to Mothers III survey—a national survey of 2400 women who gave birth to a single baby in 2011 to 2012—over 40% reported communication problems related to the prenatal care that they received, and 24% perceived discrimination during their hospitalization for birth<sup>14</sup>. In another study of 1,410 Black and African American mothers in Metropolitan Detroit, Michigan<sup>13</sup>, researchers found that women with darker complexion were more likely than women with lighter complexion to perceive discrimination in the form of microaggressions during care. Notably, these experiences appeared to affect mothers' decisions to delay or not receive prenatal care.

#### Reproductive Justice (RJ) framework

We use the Reproductive Justice (RJ) framework to critically address the experiences of parents from the Louisville community accessing or attempting to access prenatal and pregnancy care. Generally speaking, the Reproductive Justice framework prioritizes:

- a) "the right [of mothers] not to have children using safe birth control, abortion, or abstinence,
- b) the right to have children under the conditions we [mothers] choose,
- c) and the right to parent the children we [mothers] have in safe and healthy environments"<sup>15</sup>

We place the prenatal care and reproductive experiences of parents in Louisville at the center of our analysis to critically address and make changes to local policies and practices that restrict access to prenatal care and promote policies that expand equitable access to early safe prenatal and pregnancy care.

## Research Methods and Sample

We conducted 11 focus groups and seven qualitative semi-structured interviews with 34 recent parents (those who had given birth within the past three years) who had prenatal and birthing experience in Louisville. Our objective was to hear from mothers who might be less likely to access prenatal care or otherwise face barriers to accessing prenatal care, specifically Black and immigrant/refugee mothers and mothers who have experienced substance use disorder in Louisville. Demographics of the sample elicited from the interviews/focus groups, and presurvey are shown in table 1.

Focus groups and interviews were facilitated by SteVon Edwards of Schenault Solutions, LLC; James Joyce, a graduate student from the University of Louisville with training in qualitative research methods; and epidemiologists from the Center for Health Equity (CHE) with qualitative research backgrounds. All focus groups and interviews were recorded and transcribed. Because of the COVID-19 pandemic, nearly all focus groups and interviews (17 of 18) were conducted over WebEx meetings. All interviews and focus groups were recorded and transcribed by Rev.com, with additional transcript cleaning performed by the CHE research team.

We asked all interviewees and focus group respondents to complete a brief survey prior to participating in our study. This survey included demographic questions, quantitative questions about the process of receiving prenatal care, and how parents evaluated their experiences. The survey was conducted online except for individuals being interviewed in languages other than English and Spanish. We ultimately received complete survey data from 28 participants and partial data for two additional participants. An important data note is all parents who completed surveys identified themselves as women. We use "parents" to refer to our sample throughout the report because some participants did not complete surveys, and so we do not know the gender identities of all of our study sample. We use the gendered identifier, "mother" when we are referring to participants who identified themselves as women in survey data.

Interpretation services were provided by Kentucky Refugee Ministries (KRM) and Evolve502 for participants with low English proficiency. The languages included are listed in Table 2. Those parents who participated in the Spanish-language focus group also received a paper copy of the questionnaire translated into Spanish, while those speaking other languages had the survey administered to them by the interviewer and interpreter.

Table 1. Demographics

Self-Identifie R ce*	Number of Parents
Black or African American	19
White	6
Other Asian	1
Other Race	6
Self-Identifie Et mi city	Number of Parents
Hispanic or Latinx	4
Non-Hispanic or Latinx	26
Nativity**	Number of Parents
Immigrant or Refugee	9
Non-Immigrant or Refugee	25
Gender	
Female	30
Year Most Recently Given Birth	Number of Parents
2021	7
2020	11
2019	7
2018	5
Birthing Hospital	Number of Parents
University of Louisville	11
Norton	6
Norton Women's and Children's	6
Baptist Hospital Louisville	1
Non-Louisville Hospital	1
Other***	5

\*Survey categories used Census designations for race/ethnicity and are not mutually exclusive.

\*\* Though we did not directly ask participants questions about their country of origin or immigrant status, we were able to derive from sampling procedures and interview and focus group responses which respondents were immigrants or refugees to the United States and the city of Louisville.

\*\*\* We know from the interview and focus group data that some of these five parents gave birth at hospitals outside of Louisville.

Table 2. Interview and Focus Group Participant Languages

Language	Number of Parents
English	26
Spanish	3
Dari	2
Kinyarwandan	2
Swahili	1

#### Seeking Prenatal Care

All mothers who completed surveys reported that they wanted to visit a medical professional for prenatal care during their most recent pregnancy. The American College of Obstetricians and Gynecologists (ACOG)<sup>16</sup> recommends starting prenatal care within the first three months of pregnancy. Despite this recommendation, the surveyed parents reported delays beginning prenatal care. Twenty-seven of the 28 mothers who completed surveys reported that they visited a doctor, nurse, nurse-midwife, or another healthcare provider for prenatal care during their most recent pregnancy. The mother, who said that she did not visit a healthcare provider, reported that she desired to access a provider but did not. From the interview context, this mother was relatively young and housing insecure. This may have contributed to not being able to access care.

Most of the mothers who completed the surveys saw a provider within the first trimester of pregnancy, following ACOG guidelines. However, one birthing mother did not see a provider until four to five months, and another birthing mother was unable to access a provider until six to seven months. In addition, two parents reported not seeing their prenatal care provider until eight to nine months. From interview and focus group data, we know that one of these parents experienced a delay in care related to immigrating and resettling in the United States, her access to care was delayed by this transition and uncertainty about where to go once resettled.

- Within the first 3 weeks of pregnancy (n=3)
- Within 4-8 weeks of pregnancy (n=13)
- Within 9-12 weeks of pregnancy (n=7)
- Within 4-5 months of pregnancy (n=1)
- Within 6-7 months of pregnancy (n=1)
- Within 8-9 months of pregnancy (n=2)

Though our sample is not representative of parents in Louisville or Jefferson County, we note that White parents in our sample were slightly more likely to report early access prenatal care than Black parents.

There was typically a delay between the birthing parents contacted providers and when they could be seen by providers. Still, most were able to see a provider within three weeks of contacting a provider. However, some reported waiting between one and four months to be seen. The times between contacting a provider and being seen are listed below:

- Less than a week (n=6)
- One to two weeks (n=5)
- Two to three weeks (n=8)
- One to two months (n=7)
- Three to four months (n=1)

Though our sample is not representative of parents in Louisville or Jefferson County, we note that White parents in our sample were able to see providers after making contact slightly earlier on average than Black parents. Inversely, the Black parents in our sample were more likely to experience delays between when they contacted providers and when they were able to see providers.

We also asked birthing parents questions about the prenatal care supports that they wanted access to during pregnancy and which services and supports they actually accessed. Typically, mothers wanted medical services such as prenatal vitamins, nutrition assistance, and mental health counseling from a community organization or medical practice. However, there were gaps between the number of mothers who wanted various services and those who received, particularly nutrition assistance and counseling.

Supports requested and accessed include:

- Access to prenatal vitamins (n=23 wanted; n=19 received)
- Nutrition assistance (n=22 wanted; n=11 received)
- Counseling from a licensed professional (n=20 wanted; n=11 received)
- Medical services (e.g., pregnancy tests, STI testing, ultrasounds) from a community organization (n=18 wanted; n=16 received)
- Pregnancy and prenatal education/information classes or sessions (n=17 wanted; n=13 received)
- Checkups or pregnancy screenings from a non-medical pregnancy professional (e.g., a doula) (n=16 wanted; n=13 received)
- Access to substance use assistance and recovery programs (n=5 wanted; n=2 received)
- Consult with a community elder/person with more lived experience with birth (n=5 wanted; n=2 received)

#### Opinions of Prenatal Care and Provider

Overall, most birthing parents who completed surveys reported positive interactions with their providers. Most would recommend their provider to others, and most were somewhat satisfied with the prenatal care they received.

Recommending their provider to others:

- Would strongly recommend (n=8)
- Would recommend (n=12)
- Would not recommend (n=3)
- Would not at all recommend (n=2)
- Not sure/no opinion (n=2)

Though our sample does not represent parents in Louisville or Jefferson County, we note that White parents in our sample were more likely than Black parents to *strongly recommend* their providers to others. In contrast, Black parents were more likely to *recommend* their providers than White parents. In addition, Black parents were the only respondents who said they would *not at all recommend* their prenatal care providers to others.

Satisfaction with the prenatal care they received:

- Satisfied (n=14)
- Somewhat satisfied (n=7)
- Somewhat unsatisfied (n=5)
- Unsatisfied (n=2)

Though our sample does not represent parents in Louisville or Jefferson County, we note that White parents in our sample were more likely than Black parents to report being *satisfied* with their prenatal care experiences overall. In contrast, Black parents were more likely to report being *somewhat satisfied* overall with their prenatal care experiences than White parents. In addition, Black parents were more likely than White parents to report that they were *somewhat unsatisfied* and *unsatisfied* with their overall prenatal care experience.

## Focus Group and Interview Findings

Pregnancy and birthing transformed parents' lives and added purpose and meaning. Parents celebrated their stories of carrying and giving birth to children and the sense of purpose and personal growth they felt as they became mothers. For example, one parent discussed the excitement, inspiration, and strength that becoming a mother gave her:

"Hearing the heartbeat was just something that excited me every single time I went to the doctor, just hearing how he grew, seeing the sonograms. It was just so inspiring for my day-to-day activities and ambitions. And then as well as just kind of planning for how I want to parent him and what kind of mom I want to be. So that's what I enjoyed about it, because just the strength that me, as a woman, and the ability that I have to grow a whole human, it was just astonishing to me."

Most parents shared positive experiences with prenatal care providers and doctors. Many parents also said they trusted medical providers to give them accurate information about prenatal care, and they trusted providers with their lives and with their babies' lives. These parents reported that, for the most part, they felt heard by their providers and well taken care of. Additionally, parents celebrated hearing vital signs for the first time and being able to either ensure their babies were developing healthily or being able to diagnose and treat any birth complications as they arose. For example, one mother reported that many prenatal care and pregnancy team members made regular contact and ensured that everything was in order. As a result, she felt heard, valued, and that she had a say in developing her birth plan:

"I think I had an overall good experience with prenatal care. I was able to get in contact with the Healthy Start program, so I had a lady that called me every month and checked on me to make sure things were moving along great. On top of that, I also had a nurse call me, which was just with my insurance, and they called me every month as well and made sure things were okay and that the baby was just progressing along nicely, and I think that was just good to have on top of my appointments with the midwife, just to have someone that calls you at home rather than the appointment as well. So that, on top of that, was really good. I think as far as with my actual doctors; they did a good job of listening to my wants and my concerns. I got help writing my birth plan with them, so I think they actually valued what made me comfortable, what made me less nervous about delivering and just basically paying attention to my wants and needs. And it made me feel like it's about me, and they made me feel like they actually cared and listened."

Another mother said the prenatal care that she received helped doctors identify a heart condition for her baby, and now they have been able to make appointments and provide appropriate care to her baby:

"They did everything, like with vitamin and vital tracking. Also, they did an ultrasound. But at the time, they find that my baby is having a heart problem. ...

So, after that, the doctor decided to make an appointment for the cardio, the one for the heart, a doctor. And I went there, and the doctor said he would come on the day that I would give birth. ...

And on the day that I gave birth, the doctor was there. He see the baby. And now I have an appointment in September."

As has been outlined in the sections on our survey research, there is room for improvement as parents were not always able to access care at preferred stages of pregnancy or all the care that they desired.

#### Where prenatal and pregnancy care in Louisville needs improvement

We also heard from many birthing parents who had negative experiences with prenatal and pregnancy care and health care providers. In many instances, these negative experiences were traumatic and had long-lasting mental, physical, and emotional impacts on birthing parents. In this section, we outline where prenatal and pregnancy care went wrong for some of the parents that we heard from and highlight some of the ways that prenatal and pregnancy care needs improvement. First, we discuss trends where parents reported that they had difficulty accessing or finding prenatal care. Second, we discuss trends where parents reported that cost and insurance coverage deterred them from seeking out the care that they desired. Third, we discuss prominent trends where parents reported disruptions in care and communication breakdowns. Fourth, we discuss trends where parents reported that they believed their care was impacted by prenatal and pregnancy care providers who were busy or overburdened. Fifth, we discuss trends where Black mothers reported that they experienced medical racism. Sixth, we discuss parents' reports that providers were not entirely helpful in creating or did not honor parents' birth plans. Seventh, we discuss trends where providers used fear to convince parents to adhere to doctors' wishes for pregnancy and birth. Eighth, we highlight the absence of advocates for parents' wishes in the delivery room and reports that parents felt they needed to be their own advocates even at the time of delivery. Nineth, we discuss parents' feelings of isolation before and during the pandemic.

Notably, parents discussed labor and delivery extensively in interviews; so much of our data in this section speaks to these experiences. This data is relevant because parents may remember pregnancy care as a comprehensive experience and because experiences of care at the time of delivery may shape parents' views, discussion of, and the likelihood of using certain medical prenatal care providers in the future.

#### 1. Difficulty Accessing or Finding Care

Some parents either did not receive prenatal care or had difficulty accessing or finding providers. The one parent who did not receive prenatal care was housing insecure, which likely impacted

their ability to access care during her pregnancy. The other parents reported a diverse array of pathways to finding prenatal providers. Parents usually relied on the recommendation of personal networks (e.g. friends and family), service-providing care networks, or care networks (e.g. employer health insurance or existing providers). This process was sometimes reported to be stressful and frustrating because of the importance of finding a trusted provider that could provide excellent care. For example, a mother described her frustration after her previous provider retired and she was left searching for a new prenatal care provider:

"When I had my son almost 10 years ago, I loved the doctor that I had. He was so personable; he was so in tune with me, he knew exactly what to say and how to explain things so that I could understand what was going on. ...

But he retired between the time that I had my son and the time that I had my daughter, so I had to find prenatal care, which was really inconvenient because everyone will just give you a list with 30 doctors, and you don't know anything about any of the doctors, and you don't have a relationship with any of them. You just blindly pick or look at a bunch of reviews or go with someone that's close to you that have recently had a good experience, but that doesn't mean that you will have that same experience."

The parent quoted previously described being in the dark as to whether her new provider would be able to provide her with the support she needed and a positive pregnancy experience. Unfortunately, she would explain that her provider was overburdened, which led to delays in receiving important prenatal care.

This seemingly loose network of providers and organizations was particularly difficult to navigate for expectant parents who were new immigrants and refugees to the United States, many of whom lacked English language proficiency. This difficulty was compounded by delays between when parents contacted a provider and when they could see the doctor to receive care. For example, a refugee mother described how KRM takes care of mothers for three months, but after that time, parents need to seek care elsewhere:

"Because when I came here, it was in February, and after a short time, it was stay home because of the COVID. And I don't speak English, so I was supposed to find someone who can help me who speaks English to make an appointment. I was not able to make an appointment by myself. And I went for KRM because actually at KRM they take care of you for three months, and I was almost three months living in the United States, so I decided to find someone who can help me." (emphasis added)

According to this mother, a caseworker at KRM helped her to make an appointment with a provider. Still, after talking with a friend about the delay, her friend helped her to make an appointment with another provider who could see her sooner.

One mother did not get access to prenatal care until the ninth month of her pregnancy because she moved while pregnant and was not aware of where to go for care. An interpreter provided some clarification about her response to questions about that delay:

"She said that the delay in Africa, she started to see the provider at the three months when she has the pregnancy of three months. But when she came here, since she was new. She didn't know where to go. She was not aware of where she can go, no hospital, no provider. Then she has to pass through her caseworker for her to help her to see the provider." (emphasis added)

Parents pursued recommendations and made decisions about providers based on the forms of insurance and payment that providers accepted and the types of care that they supported and offered. But parents varied in the resources, time, and energy that they were able to devote to finding providers who met their needs.

#### 2. Cost and coverage as a barrier to care

Several parents could not access all the prenatal and pregnancy care that they desired due to barriers in cost and insurance coverage. For instance, parents were unable to access or continue their use of counseling services, doulas, labor coaches, medical tests for their children, and water or home births because these services and resources were not covered by health insurance or were too costly to them and their families. For instance, one mother was unable to access a doula even though she wanted one:

"Now, I feel like I couldn't afford it (a doula). But if I could, I definitely would. I definitely would have. ...

It seemed like it was an expense that I didn't have the luxury of paying. We just decided not to. Which I do feel like there are some... I know that they have programs where they can do that for you for free, or you get scholarships and things like that, but I don't think we qualify for anything like that. Then, the ones that we had looked up, they were too expensive."

Another mother of immigrant origin mentioned part of her delay in accessing prenatal care was related to cost:

"The first reason is that I was at school and I always think if the baby come, there's extra charge. We were new here, new in America. I didn't have any saving, any saved money to help me. The reason why it took me too long to go find a doctor is, it's not because I don't want to go find a doctor. It's because I was saying I will go tomorrow or next day, next day. So, yeah."

It does not appear that many parents forwent prenatal and pregnancy care all together due to costs and insurance. However, parents were limited in the type of care they could access due to costs. Parents also reported being limited to certain providers who accepted their insurance.

#### 3. Disruptions in care and breakdowns in communication

Breakdowns in the continuity of care were common issues across all parents. Parents who experienced care disruptions described a prenatal care network sometimes characterized as cold and unresponsive to their needs. Sometimes, parents attributed this to a revolving door of healthcare workers, doctors, nurse practitioners, nurses, and students. Parents expressed displeasure when they were unable to contact their prenatal care providers directly when they faced issues during pregnancy or when the providers they had worked with were unavailable at the time of birth. In some cases, parents wound up using emergency departments for prenatal and pregnancy care when they could not reach their doctor. For example, one mother reported such an instance. She was frustrated when she was unable to discuss her medical concerns with her primary doctor, and the issue that she had got worse to the point that she needed to go to a hospital:

"But later, when I started having issues with my pregnancy, it was very frustrating. Any time I would call the office to let them know, 'Okay, something is wrong. I need to speak to the doctor,' they would make me go through multiple nurses and the nurse practitioner and tell me that I couldn't talk to my doctor or see my doctor.

And it got to the point where I had to just go to the hospital because I had called them multiple times and I was in a lot of pain, and when I finally went to the hospital, I found out that I had a terrible UTI.

And each time that I went through that, I couldn't ever see the doctor. So, it just was frustrating to not be able to talk to the doctor and not be able to get an appointment with the doctor. They always wanted me to see the nurse practitioner instead, when really I just wanted to see my own doctor." (emphasis added)

When parents did have the opportunity to build rapport with a trusted prenatal care provider, often that provider was not always able to be there at the time of birth. A mother reported her frustration that the midwife that she wanted to be there for the birth of her was unable to be there at the time of birth:

"Oh, yes. Yes. Uh-huh (affirmative). Yes. Out of the whole time of my birth, I seen two. ... the one that I wanted to birth my son was not the one that birthed my son....

You go into a practice like, "I'm here to be birthed by such and such."... But then it ends up to be so and so." (emphasis added)

One mother also raised concerns about the fact that students played a large role in her birthing experience. She reflected on her desire to have more say in what students could and could not do as a part of her medical care and birth:

"I know UofL has students rotating. I don't, because I was under anesthesia, I don't know the doctor who delivered my baby. I don't remember a lot of stuff from my pregnancy. ...

I feel like I had a 'public doctor experience.' Does that make sense? Like a general, a rolling doctor, not even comfortable. ... At the end I had to start requesting the same doctor. Like no, I would rather see him. Like stop giving me new people. ...

During your appointments, it's all good. They're not doing nothing. They may check your belly and hear the heartbeat, they do that. But then when you think about being in the actual birth and a student? It's nothing against students as a thing, but it should be able to be an option and told what they will do or what they're able to do." (emphasis added)

Parents also commonly experience communication breakdowns with their healthcare providers. Sometimes parents were left wanting with how well practitioners and staff explained their health and care to them. For example, a mother wished vital signs were communicated more clearly so that she could have a better understanding of the care that she needed to receive:

"I think medically, definitely vitals. I wish that it was communicated to me more clearly or better. I just was able to get on the charting halfway through. So if the nurse or the person that took the vitals was like, 'Okay, this is it, but this is what it means,' because I had a problem of it being said I was hypertension, my blood pressure was high. And then that's part of the reason why I was induced instead of trying to go naturally.

I was asking about certain things that was happening to my body, because my hands and my foot was itching a whole lot. And of course, you're going to go to Google, you're going to ask, you're going to try to figure out."

More frequently, providers sometimes misunderstood or failed to take parents seriously when they were in pain, needed to be seen, and had concerns. Some parents had requested to be seen by their own doctor for concerns they had, and their requests were not met. In some instances, parents were not taken seriously until their conditions had become severe. For example, one mother reported that she wasn't taken seriously until symptoms and health complications became more severe, and further, that these experiences were common.

"I will say that from my experience, I felt like I wasn't listened to or taken seriously when I did have a complaint. I know a lot of other people that have had similar experiences now in Louisville where it has to get really bad before they actually do something or the pregnant mother is actually listened to."

#### 4. Overbooked and burdened providers

Sometimes parents attributed difficulty accessing care or disruptions in care to prenatal and pregnancy care providers who were busy and overburdened. Specifically, parents sometimes reported long delays between when they found out that they were pregnant and when they were able to see a provider. Parents directly attributed delays to providers being over booked. For example, a mother reported she was unable to receive prenatal care at a provider she visited for a previous pregnancy because that provider had too many patients. Ultimately, she believed that earlier care may have prevented a miscarriage, and she feared that the same thing would occur during her most recent pregnancy:

"I never even actually got in because that doctor has so many patients that she doesn't even see you until you're almost into your second trimester. When I was trying to explain I was high risk with my son, I have lots of issues when it comes to this department, I need to be seen a little sooner, and they wouldn't see me.

So, I miscarried and then I was right back pregnant again, and then I'm in the same situation, wondering and hoping that I don't miscarry. *And she still made me wait until I was 12 weeks before she saw me again*. So, I was pretty frustrated with that and the fact that just finding prenatal care was difficult." (emphasis added)

In another conversation, a mother who reviewed her provider positively reported that she would still recommend that others look elsewhere for care because of the long wait times and brevity of care that she attributed to providers being overbooked:

"I would say that if somebody had the option to not to a practice that's so big or someone that would just take more time, I would recommend that. I went to Baptist. They were great, but also, they overbooked, so you're waiting forever, things like that. So, if you could go to a small midwife or something like that where it's more one-on-one, more personable, I think that would be more helpful for first-time parents, definitely."

#### 5. Reports of Medical Racism

Several Black mothers spoke about quite severe experiences of medical racism with providers. In this study, medical racism refers to instances where it appeared or parents perceived that their (presumed) race negatively impacted prenatal and pregnancy care. The Black women that we heard from were aware of the systemic and systematic factors that make them vulnerable, which at times was reinforced within clinical settings by healthcare providers. For example, one Black mother reported that she felt the need to discuss medical racism early in conversations with providers:

"I had very open, honest conversations with my doctors and stuff like that. I remember at one point I said to my doctor, 'Now look, all these women, these Black women are out here dying. You're not going to kill me, are you?'

While there was a hint of a joke to it while we were talking, it was a very serious kind of, 'Hey. You know what's going on. Am I okay?' And he reassured me that I was and different things, different things and stuff like that."

Some Black parents felt dismissed or faced backlash when they voiced concerns regarding their health and well-being. Black parents also reported that providers responded to them and their requests in ways that reflected racial stereotypes. Trying to work with and trust providers who they perceived as contributing to medical racism was exhausting for parents who wanted the best outcomes for their child and their health. For example, one Black mother perceived that she needed to negotiate the ways that she interacted and was perceived by doctors and healthcare workers to guard against being perceived as an "angry Black woman"—a widespread and dangerous trope of Black women:

"To me, I always feel like they're going to just assume I'm going to be the angry Black woman, so I have to gauge my response, and I have to be mindful of my surroundings, and I have to watch my tone. And I have to do all of this, whether I'm in pain, regardless of how I feel so that I make sure that they do understand me. And then, even when I do present everything that way, I feel like they're just mistreating me.

One of the doctors told me that basically, it was my fault that my daughter was born early, when I had been calling y'all for three days to tell y'all that I was in pain and something wasn't right, and y'all didn't listen to me. Even those moments where I'm backed in a corner, and I still can't fight to defend myself."

Several Black mothers reported that their bodily concerns, specifically concerns relating to pain, were not taken seriously. These parents connected providers' failure to prescribe medicine for pain relief to stereotypes that Black women experience pain differently than others. For example, one Black mother reported that when she raised concerns about possible infection with her provider, her provider brushed off her concerns and accused her of just wanting more pain medication. This resulted in the infection getting significantly worse before she was able to get treatment:

"But I ended up having a C-section and afterward, I was having a lot of issues with my incision. And I told them two days after, I think, that I had come home from the hospital with my daughter, that something was wrong with my incision.

And my usual doctor was on vacation, so they made me see the nurse practitioner, and she told me that nothing was wrong with my incision and accused me of just wanting more pain medicine for my C-section, whatever the pain medication was, and told me that there wasn't anything wrong.

And then I went back a couple of days after because it was to the point where I couldn't walk, I couldn't really hold my daughter, I was struggling to move pretty much. And then they found out that it was very infected, so she apologized to me and said that she was sorry for accusing me of just wanting more pain medicine basically." (emphasis added)

Another Black mother directly connected her provider's negligence to stereotypes about Black women's experiences of pain:

"But I just basically feel like it was just a negligent thing on their part because I feel like of course, Black women are just thought of like we don't go through pain like other people do, and I feel like that just was something that they failed to do, and I'm still pretty angry about."

#### 6. Developing and honoring birthing plans

A birth plan refers to an outline of a parent's desires during labor and delivery. Several parents either did not understand the idea of a birth plan or found it difficult to ensure their birth plan reflected their desires. Sometimes parents explained their birth plan options were limited because previous complications suggested their most recent pregnancies would be high risk. Other parents generally trusted medical providers to do what was best for them and left much of their birth plan up to their doctors. However, some parents reported that they wished they had more say in how their birth plan was designed. For example, one mother felt like she gave up many of her desires:

"For me, I think just because I knew how I wanted things, but I kind of gave up on a lot of stuff in regard to my birth plan because of how things were going. So, I wish that I would have been more insistent on the things that I wanted. I really wanted to work with a midwife and doula but my husband and my mother were scared to death of me working with a midwife versus this traditional doctor. So, I think I did sacrifice a lot of stuff that I wanted in regards to my birth plan, based on what people were saying, even based on some of the things the doctor was saying to me that wouldn't be possible." (emphasis added)

In particular, the mother quoted above wanted to work with a midwife and a doula. However, she was dissuaded from pursuing this by her partner and mother, and she was also dissuaded to give up other parts of her birth plan by her doctor.

In some instances, parents described doctors as being combative and dismissive of their birthing plans. For example, one mother, who desired a home birth, relayed her distrust of traditional medical practices:

"But things took a turn early on, and I left a doctor because I didn't feel heard or understood. And I felt that he was mocking my home birth."

Several parents had developed a birth plan with their providers during their pregnancy, but at the time of delivery, their desires were ignored or abandoned without transparent communication with the parents. Some parents also expressed anguish when their birth plans were abandoned at the time of delivery. In most cases, this anguish resulted from Caesarean deliveries that were

unwanted and perceived as unneeded by the parents. For instance, a mother felt she would have needed someone present to advocate for her wishes:

"I gave them the birth plan, but honoring it, no. I feel like to have a birth plan; you need somebody to advocate for you because I don't think that they honor it unless somebody's in there to advocate for you."

The rapport developed between parents and providers was an important element of prenatal care and giving birth to another mother. The combined effect of losing her ability to follow her birth plan and the doctor that she trusted not being able to deliver her baby was distressing:

"I agree. I do think that the birth plan is really important, and I do think that building a rapport was really important. ... At the time that I had found out I had to have her, my birth plan had to go out of the window and they're telling me that I have to have an emergency C-section. So, I'm already kind of freaking out, worried about her, and then that's not my plan. So, I'm trying to adjust to that. But then a doctor delivered my baby that I had never even seen or talked to before. So, there was no rapport and I was freaking out and scared. It's a different experience when you have that rapport with your doctor and you just know what to expect going into it." (emphasis added)

#### 7. Placing fear onto mothers

When providers failed to follow birthing plans, it seemed that they frequently used fear to convince birthing parents to consent to the procedures that they recommended. Several parents who had negative experiences with providers focused on this fear and critically reflected that they felt coerced into sacrificing their birth plans or desires. According to one mother, providers told her and her partner that her life and the child's life were in danger without sufficiently answering questions that they had about their health and safety:

"I felt bamboozled, I felt lied to, so again, I'm just giving you what I call emotions going into what I'm going to tell you. So, then they bring on the... What was first. Okay. They're trying to induce me. He wouldn't dilate. Okay. And to me and my husband, the whole time, we're thinking he's not ready. He's not ready. He will come when he's ready, but they're putting this fear in us that there is no [inaudible].

... And so my husband at the time, I'm going through a divorce now, so that. But my husband at the time was like, "Okay, well, is his blood pressure okay? Is her blood pressure okay?" These are questions that we have been taught to ask. So they begin the Pitocin, and it was then I knew I had lost my natural fight, but at this point after, and I knew that once they start that Pitocin drip, you've lost your fight. But I gave up because I was in fear of my life and my son's life at this point. And to be honest, in hindsight, I feel like if I would have walked out of the hospital a second time, I feel like we would have been here. We would have been okay." (emphasis added)

Another mother believed the only negative part of her prenatal and pregnancy care experience was that doctors pressured her come in for a C-section at a certain point if her baby had not yet been born. As a result, she declined to go in and instead waited for her baby to come naturally. She suggested the fear of being pressured into C-sections by doctors is somewhat widespread:

"For prenatal care what I can say, there is a time they may tell you that the date. The probably date of giving birth to be this day and you may not need to go because of any reason can come, can you stop you to go, then when you don't go, they just start calling you saying that since you didn't come on the time or the date we told you, you will have to be, to have a C-section and that one of the problem. I heard some people are not willingly to see the provider before, how they may see them, but they still have, they still scared, because they have some different information or they may be scared by that state of being passed to C-section without being told it before. (...)

Then they just start to scaring me, saying that if you don't come today, despite not having any sign, anything, then I was scared, but I just waited and waited. I just go to the hospital when I saw my first sign, and I give birth very well, no problem. No C-section as they were expecting. That's what I didn't like for the prenatal care only.

Then it's good to let us be, to let women to be by themselves, to be responsible for what will happen. To not force them to go before time. You may go before time and spend days and days, and you know this life, it's not easy to spend days in the hospital. It's good to let the women to be by themselves sometimes, but not let them, if you may help with them, but not let, not force somebody to go before time. That is what I can say and everything else is good."

#### 8. Feeling that mothers need to be their own advocates

Many parents iterated some version of the statement that mothers needed to be their own advocates when it came to caring. For some parents, their reports were celebratory. They were able to advocate for themselves and they felt heard by doctors. However, for parents who had negative experiences with providers, who had serious birth complications or emergencies related to their pregnancies, and who had to contend with medical racism, being one's own advocate could prove exhausting and defeating, especially at the time of birth. One mother was able to advocate for herself but also was able to build a team that supported her wishes and birthing concerns:

"I mean, definitely advocate for yourself, and find people, and go to places that will advocate for you. I think all of the people I came in contact with were very supportive of me. They listened to me. They believed what I was saying. They took me seriously. They never questioned anything that I said, no matter how silly it was.

I had really bad carpal tunnel with this second pregnancy, and there ... When I first brought it up, it was, 'Hey, this is completely normal. That's a completely normal pregnancy symptom.' Then, it continued. It got worse. I told them, and they're like, 'Well, that's normal. We'll do this.' They ended up recommending physical therapy and different things that actually helped." (emphasis added)

Another mother was exhausted from having to advocate and defend her desires to providers.

"To be completely honest, I had to have a C-section my first time and I knew I had to be an advocate for myself because they wanted me to have another C-section. Every time I went in, they just kept telling me how I had to have a C-section. And I was annoyed by that. They wanted to strip my membrane. Because everything happened so fast, I was already making end of delivery decisions in September and October. And I was due March 1st. So, I was annoyed with that. ...

And so just having to ... vouch, advocate for myself, everything I ate, or they were really on me about my health, saying that I was high risk because of my age and my weight." (emphasis added)

Conversations about advocating for oneself were often connected to broader discussions about the lack of advocates for birthing parents during the time of delivery. Parents sometimes described a delivery room where the size of the medical team and the authority they had seemed to simply overpower the desires of parents. Additionally, while parents emphasized the importance of advocating for oneself, it was evident that this was difficult at best when things went wrong in the delivery room. One mother described the near impossible task of ensuring her birthing plan was followed with so many different parties in the room while she was "tied up and going through pain" during the birth.

"No, uh-uh (negative). I could have been up in there when I came there in my contractions with a piece of paper and said, 'Here's my birth plan. Everybody get a copy.' First shift, third shift, second shift. No matter what's your period. They're in my room. When you come in my room, here's my birth plan. You know what I mean? But when you got you tied up and going through pain, how do you spell birth plan? But my doula was working, was trying, ... you can't go back and go behind the counter and call somebody. If they're not working today, they not working today."

Another mother's birth plan was not followed at the time of delivery. She iterated that a requisite to the birthing plan being followed is that an advocate be in the room at the time of delivery.

"I gave them the birth plan, but honoring it, no. I feel like to have a birth plan, you really need somebody to advocate for you because I don't think that they honor it unless somebody's in there to advocate for you."

#### 9. Feelings of isolation prior to and during the COVID-19 Pandemic

Although pregnancies were generally a time when friends and family celebrated parents, people giving birth frequently felt socially isolated from partners, family, and friends and lonely. For example, some parents reported that male partners did not understand what they were going through, and because they were men, their partners were limited in the emotional support they could offer. Others grieved the loss of mothers and grandmothers who could provide guidance and understanding. Still, others reported that they felt distant from relatives who had previously given birth because of how long it had been since these relatives were pregnant or gave birth. And still, other parents felt estranged from friends who were not pregnant or who had not been pregnant. One mother described this feeling of isolation:

"I didn't have the emotional support during my pregnancy that way. I didn't have that really from anyone but my spouse, and he really just didn't get it because he's a man. ...

And then, when you're pregnant and all your friends are just living their best lives and you don't really get to interact as much. So, there was distance there."

Another mother suffered postpartum depression, which she connected to her feelings of isolation and traumatic birth experiences:

"So, I'm thinking I can't even give birth right. I can't nurse. So, then the post [inaudible]. I got really depressed, really depressed. My hair was falling out. It was that easy, and none of our friends had children. So, they did not understand. And I got really alone, really alone."

Feelings of isolation and loneliness were amplified by the precautions that providers took during the COVID-19 pandemic. Partners and families who were previously able to attend appointments and births had restricted or virtual access. For instance, one mother responded to the question: What was it like trying to access prenatal care during COVID?

"Oh, definitely different. Definitely different. *The biggest thing, you lose your support*. My first pregnancy my husband was with me at every appointment. Most of our questions were answered, things like that. We would come up with lists. The doctor would look at him like, 'you got anything?'

This time around, it was all on me. I was at the appointments by myself. That was strange. Just losing your support and the other person who's helping you make the decisions on care and just if you need to know anything, and just the other person who's helping you try to make sure you're thinking about everything, thinking through everything." (emphasis added)

In summary, most parents reported many positive experiences with prenatal care. Parents trusted providers, felt heard, and felt well taken care of. Still, there were places where prenatal care

could be improved, and there were parents who sometimes reported traumatic prenatal, pregnancy, and delivery experiences. Some parents reported that accessing prenatal care or knowing where to go to do so was troublesome. This may be particularly true for parents who are recent immigrants or refugees or who have newly come to Louisville. Cost and insurance coverage prevented some parents from receiving desired types of care. Disruptions in care and miscommunications were common across reports, and this may have been in part due to providers being overwhelmed or overloaded. Black mothers reported medical racism from providers, especially around the time of delivery or when they requested pain treatment. We also heard from parents who reported that providers were ambivalent or dismissive of birth plans and used fear to convince parents to abandon these plans when complications arose during pregnancies or deliveries. Parents felt like they had to be their own advocates, which highlighted that parents may be unable to do so at various points of pregnancy, and there was an absence of or lack of available advocates during pregnancy and delivery. Parents who gave birth before the pandemic reported feelings of isolation, but it seems that the pandemic may have made these feelings more severe.

#### What birthing parents' value / want to see in prenatal care

This section focuses on what parents valued or wanted from providers and health care systems. First, we discuss parents' emphasis on mutually building relationships and establishing rapport with their providers. Second, we discuss a related trend: parents had positive experiences when they felt that providers listened to and heard their requests and discussed their experiences with pregnancy and birth. Last, we highlight the trend that parents wanted to see the increased representation of Black women as providers in pregnancy and prenatal care spaces.

#### 1. Emphasis on relationships

Regardless of whether they had positive or negative experiences with prenatal and pregnancy care, nearly all parents expressed the value of building relationships and rapport with their providers. Parents who had established positive and trusting relationships with providers were comfortable asking their providers questions and felt those relationships were central to having positive experiences with prenatal care and pregnancy. Conversely, parents who were unable to develop rapport or did not have established, trusting relationships with providers wanted these relationships and reported that this was a crucial place where their prenatal and pregnancy experience went wrong. For example, one mother who had positive relationships with prenatal care discussed the importance of developing these relationships:

"My point is I think when people have open, honest conversations just things turn out okay. I had great prenatal care. I had honest conversations. They knew my fears and things that I was anxious about, and they reassured me that everything would be okay, and it did two times. It ended up being great, you know?"

Additionally, a mother said the simple act of being checked on by her provider when she had to receive other medical care made her feel well taken care of:

"And also, a few times, I went to emergency room and the doctor checked on me. And so usually, the doctors won't do that, but that was very nice of my doctor."

Parents valued relationships, especially when pregnancies did not go exactly as desired and planned. For instance, one Black mother shared that even though she wasn't able to carry her pregnancy to full term, her provider's warmth and empathy and the relationship that she was able to build with her provider made the experience a positive one:

"They induced me at 38 weeks, so I didn't carry completely full term, but they were very warm and attentive. That OB, in particular, I will go back to her if I get pregnant again because she was just so... To me, I was like, 'I need empathy. I need warm. I need you to be tuned into me being a first-time mom.' I needed her also to demonstrate that she had some kind of cultural awareness. I told her about my concerns as a Black mother to be and other stories I had heard of black moms not getting the prenatal care they deserved, and to me, she seemed culturally competent. She seemed warm and she ensured that I did get the best care." (emphasis added)

#### 2. Where mothers felt they were listened to

Feeling heard was an important part of parents establishing trusting relationships with prenatal and pregnancy care providers. Most of the parents who shared positive experiences with prenatal care said providers listened to their concerns and desires and took them seriously. For instance, a mother who traveled across state lines to receive prenatal and pregnancy care from a CABC accredited birthing center affiliated with a major hospital felt taken care of and attributed this to the fact that she felt that lines of communication were clear between her and her providers.

"I can honestly say that the ladies who took care of me... most definitely felt heard. I felt very informed about what was going on with me, very direct. The ladies were very helpful when it came to mental health during and after pregnancy." (emphasis added)

Another mother felt supported by her midwives. She felt that they listened to her concerns and treated her with respect when she had questions about her care:

"Definitely the rapport, like they said, and then I liked that I could always call my midwives. They didn't make me feel stupid about asking whatever silly question I had. My birth plan for the first pregnancy did not go at all like I planned for it to, so with the second I wanted to do a VBAC, but I went into it just kind of open-minded knowing that I might not be successful in having a VBAC. But ultimately, I was." (emphasis added)

In contrast, parents who reported negative experiences with prenatal and pregnancy care felt that they were not listened to. As we highlighted in the sections on miscommunications and birth plans, parents sometimes felt mocked by providers for their wishes and prenatal and pregnancy care preferences.

#### 3. Desire for Midwives and Black women in prenatal and pregnancy care spaces

Black birthing parents expressed a desire to see the increased representation of Black women among pregnancy and prenatal care health workers. Parents also emphasized that they wanted nurse-midwives and Black women to be responsible for their care. For example, one Black mother selected her prenatal care and birthing hospital because they offered midwives and because two of the midwives that that hospital offered were women of color. Other parents who sought midwives reported that UofL hospital was the only hospital in Kentucky that offered midwives to expecting parents:

"And so, I went to the UofL because Dr. Franklin was there and they had midwives, and two of the midwives are women of color."

Parents believed that having providers of color would help to resolve some issues, particularly those pertaining to medical racism and understanding the experiences and perspectives of women of color. For instance, one mother's experiences with prenatal care and giving birth were better than her previous pregnancies because the midwife she worked with was more responsive to her needs and desires than other providers:

"In Louisville, it was better because at Louisville Hospital they offer midwives there. I did choose a midwife to do my appointments with, and you also have to do a OB. I feel like that experience was better because she was more patient. I think she was more honorable with my birth plan than the doctors or the OB was, but she was a very patient person and she knew that births take time and she honored everything that I wanted. She answered all my questions and my concerns. And she was with me through the process." (emphasis added)

Another Black mother strongly desired to have a woman of color in charge of her care because a previous provider had dismissed a medical concern that wound up being serious. In addition, she believed that a woman of color would be more understanding of the ways that providers dismiss people of color's medical concerns. As a result, she hoped that they would provide care that adhered to her concerns and needs:

"This pregnancy, I was very adamant that I wanted a person of color, specifically a Black woman at the head of my care.

My first pregnancy was smooth, but after the doctor that ended up delivering my first kid, the nurse had mentioned my stomach looking odd, and it wasn't the doctor that I had the

whole time, that I was seeing the whole time because she was not on call that night. And so the doctor, she just waved her hand, and said, 'Oh, she has a fibroid. That's it.' I go to the room, and discharged, come back the next morning, find out that I have an umbilical hernia, and so I'm like, 'You dismissed that.'" (emphasis added)

Another mother similarly wanted to see increased representation of Black women in prenatal and pregnancy care spaces. She linked this desire to her positive experiences with Black health workers during her second pregnancy:

"I would say just more representation as far as Black women being midwives, and lactation consultants, and all of that. Because my first son, I had no idea of course when it came to breastfeeding. And comparing my experience in the hospital after I had him to the one with my second son, I definitely felt like my second son, they treated me way better when it comes to breastfeeding." (emphasis added)

Some participants expressed a desire for more Black women in pregnancy care spaces but were clear that increased representation would not be enough to completely address medical racism in prenatal and pregnancy care.

In summary, parents value building trusting relationships and rapport with providers. Parents wanted to know the people who provided pregnancy care, including at the time of delivery, and they wanted to be sure that these providers held their desires and interests in high regard. Parents reported positive experiences with pregnancy when they felt heard and taken seriously and reported more negative experiences when they felt that they were not. Black parents expressed a desire to see more Black women and nurse midwives responsible for pregnancy and prenatal care, and parents who worked with them frequently reported positive experiences. Parents believed that these providers would provide care that was more responsive to their needs and desires and more culturally competent.

### Non-Medical Prenatal Care Support

Our research team was particularly interested in understanding parents' experiences, desires, and perceptions about non-medical prenatal care and support. This section discusses some Black mothers' discussions about the desire for alternatives to hospital and medical prenatal and pregnancy care. Second, we highlight potential gaps in helping navigate prenatal and pregnancy care as well as one place that we saw resolution for this gap. Third, we reiterate that parents reported a gap and a desire for more advocates, such as doulas, for their wishes in pregnancy and prenatal care spaces. Fourth, we highlight parents' value on learning from mentors or more experienced parents, which sometimes involved their mothers. Finally, we highlight the value and desired increase in collective groups that offer support.

#### 1. Birthing options

Most parents preferred to receive prenatal and pregnancy care from medical providers, and most of the parents that we heard from reported positive experiences with the medical providers they encountered. However, some parents expressed a desire for alternatives to giving birth at formal medical practices. These desires frequently involved discussions of home births or CABC accredited birthing centers and methods of delivery like water births. While parents expressed various reasons for preferring these methods—for some, it was spiritual reasons or based on past negative experiences, or a combination—a general theme was a sense of distrust in hospitals and traditional medical institutions. Parents expressed the desire to have more control over their birthing experiences than many medical practices permitted and felt home births or CABC accredited birthing centers would allow them the agency to follow their desired birth plans. Unfortunately, this plan was not always met with respect from doctors. Many parents felt that their doctors were not listening to and respecting their desires, which had a negative impact on their birthing experiences. For example, one mother reported looking into natural birthing experiences because of a traumatic experience with a prior birth:

"So with that, when I was pregnant with my daughter, I just really deep dug into research, natural birthing experiences, and where I could possibly have a water birth or something along those lines, because I have a son who's nine years older than my daughter, and I had a very, very traumatic experience with having him to the point where they used the suction to pull him out, and end up cracking his skull, and he became severely anemic because his placenta detached before he was out of me, and he end up having to take morphine, and he was jaundice, and it was just a really traumatic experience, which is probably why my children are so apart because it took about that long for me to even think about having any more children, especially in the hospital setting." (emphasis added)

Another mother believed home birth offered her control, comfort, and protection in comparison to the hospital, which she describes as cold and being in the hands of strangers:

"I feel like it's more of a relaxed environment. You don't feel rushed. You're in your own space also you're around your family and it's just like a circle of protection all around you. You're not outside of your element.

When you're in the hospital, you're outside of your element. You're basically in the hands of strangers, even though you see your doctor all the way up until. They're skilled nurses, and then you kind of hooked up to all these machines and it just really depends on the situation, but walking around and you don't really have as much freedom as you do when you're at home."

Additionally, another mother who wanted to give birth in the water reported that she wanted to do so because water was sacred to her:

"They knew my birth plan. I was very adamant that I wanted to birth in water because water is sacred to me, and it was important."

Such births were not accessible to all parents who wanted one. This was commonly attributed to financial and logistical or legal constraints. Specifically, equipment and support for at-home water births were prohibitively expensive for some parents, especially because insurance is not accepted for these costs. According to several reports, Kentucky laws have prohibited midwives from practicing independently and from attending home births. Though we heard that many birthing parents delivered at hospitals with birthing pools, hospital policy restricted the use of these pools to pain management. Therefore, parents were not permitted to give birth in pools. For example, one Black mother was under the impression there may be some laws that prevent mothers from giving birth at their homes. She believed that mothers should be able to give birth where they want to:

"I'm not sure if they have changed this yet, but birthing at home, if that is made into law now. That was my biggest thing, women to birth where they want to birth."

Another parent reported not being able to have a home birth or doula because they did not accept regular medical insurance:

"I know with my last pregnancy, I wanted to do an at-home birthing, and I wanted a doula. But when I tried to look into it online, because I didn't have a... Or talk about it instead. This was in the beginning, when I first found out on... It was policy, and I don't think they accept regular medical insurance. They preferred cash, so I wasn't ready for that. So I just decided to go into a regular hospital"

We heard from parents who looked outside of Louisville for prenatal and pregnancy care. One mother discussed traveling three hours away to receive the care that she desired and to give birth in the way that she wanted to:

"So researching, I found that in Kentucky, midwives aren't allowed to practice independently. The only place where they said there were midwives was U of L, and I looked into that, and found out even with the water birthing tub, they don't allow you to give birth in the tub. Ask them if I wanted to just stay there. They said no. What would happen is for pain management you can be in the tub. And then when it was time to push, you had to go back onto the bed, and I didn't care for that because that's not the experience I wanted...

So, I continued my search to find a natural birthing facility, and the closest ones I've seen were in Cincinnati and Nashville. So, what I ended up doing was going to Nashville for my prenatal care...

The only downfall was it was three hours away. I wished that Louisville did have a facility that ... imitated the place that I had my daughter at."

Unfortunately, the parent quoted above went to labor in Louisville and was five hours into labor when she received medical assistance because of the commute to give birth in the way that she desired.

#### 2. Navigating prenatal and pregnancy care spaces

As discussed earlier, navigating prenatal and pregnancy care spaces was sometimes a stressful process and may have been more difficult for parents who did not have a direct connection to networks that could guide them to resources or information that would help them during their pregnancies. A few parents discussed web-based resources that they were aware of or stumbled upon and advised that other expecting parents take advantage of these resources. However, it seems that several parents were simply left to find this information for themselves—which could be dangerous if parents receive and act on misinformation. For instance, one mother reported frustration with the gap in information about what to expect during pregnancy and delivery:

"No, so they really didn't explain a lot to me about what was going to happen that day. I didn't even know what I was supposed to take to the hospital for the day. What do you pack in the hospital bag? I didn't really know. What the entrance of the hospitals? Like I had to be induced and I wasn't really prepared for what was going to happen that day. I did watch a lot of YouTube videos, kind of like educating myself on what the experience was going to look like." (emphasis added)

Parents who had recently immigrated to the U.S. or otherwise had limited language proficiency reported receiving help from organizations like Americana and caseworkers who helped them to navigate prenatal care spaces. For example, one immigrant mother reported that a caseworker helped her make an appointment with a doctor when she found out she was pregnant during the COVID-19 pandemic:

"The first day when I recognized that I am pregnant, it was not easy because we were in the COVID time. But I informed my caseworker at KRM, and she made an appointment our doctor, a doctor."

#### 3. Advocacy before, during, and after birth (Doulas)

When medical professionals did not honor birth plans in the delivery rooms, parents tended to describe the delivery room as adversarial. At times it seemed like there were not advocates to ensure that parents desires were heard and considered by medical teams. Parents expressed a desire for increased access to doulas to provide the level of advocacy they could not always maintain for themselves during the birthing process. However, some parents indicated that doulas could be difficult to find and unaffordable.

Interviewer: Why do you think that support is important? (referring to a friend who was not a certified doula but offered support that a mother reported was what a doula would have done.)

Mother: Because when a woman is birthing a child, that kind of takes over everything. You don't have time to worry about any other thing, except for this baby coming through. Not only were they advocating for you in the hospital. **And there were certain things** 

that I didn't want to happen to my baby or me, that she was able to convey that to the doctor, without me worrying about it. But I couldn't because I was in labor. She was there with my voice when I couldn't be my own voice and there just to assist in the birthing process because I don't know what I would have done without her in those types of things.

#### 4. Guides or mentors

Many parents discussed the value of or iterated a desire for advice from guides or mentors who had more experience with pregnancy than they did. For some, this meant seeking advice and guidance from their mothers or other family members who had experience with pregnancy. They recognized that they could not go to their doctors for everything and that there was a valuable experience in their families and networks that could help them ensure that they got the best care possible for themselves and their babies. Unfortunately, such guides or mentors were sometimes missed when parents felt they were unable to go to their family or friends for guidance and support. For example, one mother described a gap in her support system after her mother passed away:

"I definitely understand that. That's how I felt. *I didn't have the emotional support during my pregnancy that way.* I didn't have that really from anyone other than my spouse, and he just didn't get it because he's a man. *I'm the oldest woman in my family and the there's not anyone else. So I didn't have it family wise.* 

. . .

I mean, for non-medical support, I liked having a doula. She would text me all the time and see how I was and give me support that way. ... But I like the idea of the elders. When I had my son, I had that support from my mom, but she had passed away a few years back so I was lacking in that." (emphasis added)

Some parents were able to leverage personal networks to access friends and family who had unique expertise as it pertains to prenatal and pregnancy care. Some parents had friends and family who were doulas, lactation consultants, nurses, or worked in other professions that enabled them to locate support for parents. One mother went to her sister who was in nursing school for her questions about pregnancy and birth:

"It is very important if anyone has pregnancy experience to listen or to share their experience. ... It is good to share what to eat or what to do from an experienced person, because they went through the same thing. And personally myself, I have a sister in London. She went to nursing school. So, I would share if I had a question. Beside my doctor, I would ask her recommendation what to do."

### 5. Support groups (formal and informal)

Several parents were either involved in formal or informal support groups for expecting and new mothers. Parents discussed in-person support groups hosted by community organizations, virtual spaces such as Facebook groups, or other support groups that became digital during the pandemic. Some parents who did not have access to such groups believed these kinds of resources would be very helpful for expecting parents. Parents who gave birth during the COVID-19 pandemic reported missing out on getting to physically attend support groups with other parents to discuss their pregnancies. Many of those mothers who did not report involvement in support groups expressed an interest in formal and informal groups where mothers could offer guidance, advice, and could share concerns. For example, one mother discussed the value of her experience getting to discuss her pregnancy with other expecting parents:

"It was a complete 180 from what I experienced with my son. We were able to take birthing classes with other soon-to-be parents. There were events for us to get together throughout the pregnancy for classes on what was going on and changing with our bodies for different women that were due around the same time, so there was a lot of resources and a lot of help."

Two other mothers agreed that support groups and education from experienced mothers would be helpful in terms of offering guidance and comfort to parents:

Mother One: "Maybe if these women, they have someone who already gave birth like a family, friends support, and also I think educational support, because knowing what's going on with you and your body during the birth process is very important and it makes you a calmer when you know what to expect."

Mother Two: "Yeah, I agree with the educational part. And maybe if somebody doesn't have a friend or family member who are pregnant before and who can walk alongside them, some support group where you can share with other mamas."

Mother One: "I think network classes, were kind of a good option before COVID because you can meet the other mamas. But I think online, even if you have prenatal classes online, it's really helpful."

In summary, we asked questions specifically about non-medical forms of prenatal care and support that parents found valuable or wish they had access to during their pregnancies. Based on interview and focus group data, we found that parents who had negative experiences with formal medical practices or a general distrust sometimes expressed a desire to access alternative birthing options such as birthing centers, home births, and water births. Parents also reported that they needed or expressed an interest in resources that could help navigate prenatal and pregnancy care in Louisville. Parents had to do their own research at times, which could lead to misinformation. We found evidence that parents of immigrant origin or new to Louisville might face particular difficulty navigating local prenatal and pregnancy care networks. Parents needed

or wanted advocates such as doulas during prenatal and pregnancy care and at the time of delivery. They also found mentoring relationships with other parents—frequently their mothers—valuable, and parents who missed out on these relationships felt their absence. Parents valued and expressed interest in support in group settings such as listening or educational groups.

### Support during or after birth

Although this study was intended to be focused primarily on the prenatal care experiences of recent parents in Louisville, parents discussed important gaps in support or care shortly after giving birth. These conversations frequently occurred at the end of interviews and focus groups when we asked parents if there was anything else that they wanted us to know about pregnancy and prenatal care in Louisville. These trends warrant attention because they emerged organically from parents' discussion of their care. In particular, parents reported important gaps in their ability to access mental health services as they grappled with their sometimes-traumatic pregnancy and delivery experiences and postpartum depression. They also identified gaps in support for initiating and successfully breastfeeding after birth. In this section, we outline these themes.

### 1. Desire for access to mental health services

Many parents who described their experiences related to mental health and postpartum depression frequently talked about the lack of support they had. For these new parents, feelings of isolation were common. They described feeling like they were doing this all on their own without any familial or medical support or that they had failed as mothers when they had difficulty or were unable to breastfeed. Many parents said that they wish they were able to talk to other new parents who were going through postpartum depression as well. For example, one mother described a desire for more resources to be available to mothers who are grappling with postpartum depression:

"But anyway ... so postpartum is so real. ... I think that there definitely needs to be more conversation, more resources for that. More access to mental health providers."

Another Black mother described wanting more spaces for women of color to discuss postpartum depression and their sometimes-traumatic birth experiences:

"And so then I feel that I have to be quiet about my trauma which again is internalizing hurt and pain, which is not healed, because I don't feel that I have the equal right to go about this, you know? ...

But I'm just saying this because I now know that I am not the only individual who is, and I'm not the first to feel these type of emotions. So if we could have more safe places or especially women of color. And I say that specifically because there are not a lot of places where we feel safe to open up like that. So I think that creating safe places for new mommies of color perhaps night became through."

### 2. Desire for breastfeeding support

Some parents expressed the importance and need for breastfeeding support after giving birth. Overall, parents wanted to have a positive experience at the hospital where someone, whether it be a lactation consultant, doctor, or nurse, supports them and shows them how to breastfeed properly. However, some parents conveyed that the doctors did not give them enough support when it came to learning how to breastfeed. Parents also did not feel supported when there were difficulties attempting to breastfeed. For example, some parents were not provided a lactation consultant while in the hospital, which led to stress and disappointment. Other parents were told they could not breastfeed in general, after which the parent learned from another source that they could breastfeed. For example, one mother emphasized the importance of supporting breastfeeding and also shared that she felt undermined when medical staff fed her newborn Similac bottles without consulting her while she was trying to breastfeed:

"There is one last thing. To support breastfeeding, acknowledge breastfeeding, there was some different, I think I had to find my own lactation consultant, but I didn't even really need them to, because I got it through my insurance. ...

And then when I was at the hospital during my birth, I made it clear that I was breastfeeding and nursing, and then he was in the NICU for jaundice. ...

they were trying to feed him the little Similac bottles and stuff ...

I think that right there, that was a big thing. That's one of the reason why I went to midwife, or midwifery practice, because that's what I wanted, to have support in all those areas."

Another mother shared that she was told that she would be unable to breastfeed. But because she desired to, she looked into breastfeeding for herself and was able to get some direction on how to get to a place where she could breastfeed:

"It was just very traumatic. They told me during the issues with my incision that I couldn't breastfeed, but because of where I worked I was able to call a research line in Texas where they research medication interactions with breast milk, and they told me points during taking the medication where I could breastfeed and how to maintain my milk supply and everything because breastfeeding was really important to me. But the doctor did not try to work with me on that at all."

Though we did not initially ask questions about support during or shortly after deliveries, several parents reported a local need for mental health services and improved breastfeeding support following delivery. Postpartum depression, pregnancies, life changes, and their sometimestraumatic experiences in delivery impacted their lives and relationships far after deliveries. As a result, improved access to counseling services focused on these experiences were needed by the parents we heard from. Some parents also reported that they did not receive what they believed was enough breastfeeding support and they wanted to see improvements in that area.

## Policy and Practice Directives

This section discusses policy and practice directives that came from our survey and interview and focus group data. Some of these directives were explicit when parents directly stated what they felt was missing in prenatal care and what needed to be addressed by legislators and medical practice, and hospital administration. Others were derived from themes repeated in the focus group and interview data.

The <u>Black Mamas Matter Alliance</u><sup>17</sup> outlines eight standards of care that should be prioritized as clinicians, health workers, and we add policymakers recreate equitable maternal and pregnancy care systems. These eight standards are:

- 1. "Listen to black women."
- 2. "Recognize the historical experiences and expertise of black women and families."
- 3. "Provide care through a reproductive justice framework."
- 4. "Disentangle care practices from the racist beliefs in modern medicine."
- 5. "Replace white supremacy and patriarchy with a new care model."
- 6. "Empower all patients with health literacy and autonomy."
- 7. "Empower and invest in paraprofessionals."
- 8. "Recognize that access does not equal quality care."

Notably, our following recommendations parallel these recommended standards.

In what follows, we first outline the need for providers to listen and be responsive to parents and mothers. Second, we identify the need for increased access to caseworkers, doulas, and other advocates for parents during prenatal and pregnancy care. Third, we explore the desire for increased support and guidance in group settings. Fourth, we discuss the need to increase the number of providers who offer prenatal and pregnancy care in Louisville to alleviate the current burden on providers and the desire for an increased presence of Black women and midwives among prenatal care providers. Fifth, we discuss the desire for birth options, such as: births outside of the hospital, VBAC, unmedicated, and models of care such as midwifery and potentially a center that offers such options in Louisville. Last, we discuss the need for increased mental health and breastfeeding support following pregnancies.

# 1. Ensure providers work with and respond to parents and mothers to ensure that they feel heard

The parents who felt that providers listened to them and were responsive to their concerns and desires reported positive experiences with pregnancy and appeared more likely to return or recommend their providers to others. Therefore, advocates and providers in Louisville's prenatal and pregnancy care spaces need to focus on ensuring they create practices that listen and adhere to parents' concerns and desires. Building a health system comprised of culturally sensitive providers who are responsive to parents' needs and respectful in communication when issues

arise can help parents make informed decisions about their health and pregnancy in a way that helps parents feel heard and respected.

Some of this involves reducing the burden of overbooked and overwhelmed providers (to be discussed). However, some of this—particularly for Black mothers—involves addressing implicit and explicit bias in local health systems. Recall that studies 13-14 have demonstrated that perceived discrimination affects perceptions of care and the likelihood that mothers will delay or forgo accessing prenatal care. Professional medical organizations have released statements and may be able to offer direction regarding policies and training to address individual-level racism pertaining to Black women's health. For instance, the ACOG released the following "ACOG is committed to eliminating disparities in women's health and to confronting implicit and explicit bias and addressing the way in which health care systems perpetuate inequality" <sup>18</sup>. They have prioritized advocacy for legislation such as the Preventing Maternal Deaths Act, the Maternal Health Quality Improvement Act, and the Helping Medicaid Offer Maternity Services Act. ACOG also works to reduce disparities in maternal mortality through the Alliance for Innovation on Maternal Health (AIM). Which is a cross-sector maternal safety and quality improvement initiative focused on increasing and supporting evidenced-based maternal safety best practices<sup>18</sup>. Area policymakers, providers, and advocates should look at the support and examples that AIM might be able to provide. However, it should also be noted that the Louisville community is home to a wide-range of professionals and organizations who could offer insight and guidance towards addressing individual-level racism in medical practices.

# 2. Increase access to caseworkers, doulas, and other advocates for parents during prenatal and pregnancy care

Advocates and providers in Louisville's prenatal and pregnancy care spaces need to focus attention on increasing the number of caseworkers and doulas who can provide assistance and advocacy for expecting parents and increase access by supporting policies and programs that make these resources affordable to parents. Critically, barriers to receiving these services need to be removed as well. This includes cost or insurance coverage and ensuring parents are well informed of their options. The advocates themselves (whether doulas, case managers, navigators, or others) should also be well-versed in the array of options for parents and be prepared to respond to the culture and belief systems of the parents with respect to things such as their birthing plans, nutritional needs, and breastfeeding. However, increasing the availability of advocates also requires that medical teams respect and welcome these advocates as valued members of the care team.

The National Academy for State Health Policy (NASHP)<sup>19</sup> outlines examples of policies at the state level in four states that aim to increase access to doulas in efforts to decrease health inequalities between White and Black pregnancies. In the four states that they highlight—Indiana, Minnesota, Nebraska, and Oregon—Medicaid programs are used to provide access to doulas for eligible families. In Kentucky, HB266, which failed to move out of committee in 2021, which would have allowed for Medicaid reimbursement of doula services. However, advocacy around the benefit of these services should continue to support future opportunities to

pursue similar policies. Institutionally-driven programs and policies to provide better access to doula and other services may be another mechanism to increase availability.

Norton Healthcare<sup>20</sup> is piloting a community-based doula program that provides doula services to mothers who live in California, Portland, or Russell neighborhoods. We recommend that advocates follow this pilot program and seek to replicate or otherwise expand who has access to these programs.

### 3. Increase support and guidance in group settings

Based on these trends, we suggest that advocates and supporting organizations in and connected to Louisville's prenatal and pregnancy care spaces should provide opportunities for support in group settings to help connect expectant parents with a support network. Scott et al.<sup>10</sup> find that participation in group prenatal care programs is associated with significant reductions in preterm births, low birth weight, and the hospitalization of infants in neonatal intensive care units. They suggest that although group prenatal care alone cannot address disparities in prenatal care, prenatal care access, and health outcomes, group prenatal care presents an opportunity to improve health outcomes for targeted groups.

There are a variety of models of group care, such as <u>CenteringPregnancy's model</u><sup>21</sup> that combines individual wellness checks and group discussions. Such models may help alleviate feelings of isolation that parents expressed or the need to connect with elders and mentors with more experience when those individuals are not present in the parents' lives.

Fortunately, several of the community organizations that referred study participants to us already host groups where mothers can come together and discuss their pregnancies. We suggest that community organizations continue to invest in and expand these opportunities.

### 4. Increase the presence of Black women and Nurse-Midwives in OB spaces

Reports suggest that local providers are overburdened, and action should be taken to alleviate the burden on our current prenatal and pregnancy healthcare systems. For example, the Association of American Medical Colleges (AAMC)<sup>22</sup> is projecting a physician shortage between 37,800 and 124,000 by 2034. They further report that "if healthcare access were equitable across race, health insurance coverage, and geographic location, the United States would require up to 180,400 more physicians as of today"<sup>22</sup>. Similarly, Stonehocker et al.<sup>23</sup> suggest a current shortage of OB-GYNs that will worsen in the future. Therefore, advocates and providers in Louisville's prenatal and pregnancy care spaces need to focus on increasing the number of practices and providers offering prenatal and pregnancy care services for Louisville's parents.

Recall also that Black women reported wanting to see an increased representation of women of color as providers in maternal and pregnancy care spaces. According to Rayburn et al.'s<sup>24</sup> analysis of U.S. national data from professional and student medical organizations (The Association of American Medical Colleges Student Records System, the Association of American Medical Colleges Minority Physicians Database, and the American Medical

Association Physician Masterfile.), of 190,379 total physicians, OB-GYN were the most likely to be female (61.9%) and had the highest portion of underrepresented groups (18.4%, Black 11.1%, Hispanic 6.7%). In addition, Black women represented 13.2% of the OB-GYN workforce in 2014<sup>24</sup>. In comparison, 24.2% of the female population that is 15 to 44 years of age in Jefferson County is Black or African American according to 2019 American Community Survey 5-year estimates.

Based on reports and requests from Black women and the aforementioned shortages, we suggest that practices should prioritize recruiting and retaining Black women providers, and area hospitals and practices should employ nurse midwives as they seek to alleviate the burden of overwhelmed providers. Policymakers should consider expanding the ability of nurse-midwives to practice independently or the spaces that they can work in.

Investments and efforts should be made to create an infrastructure to attract, train, and retain Black women providers such as residencies, funding opportunities, and early recruiting opportunities and experiences for children and young adults who may be interested in medical professions.

5. Promote options for births outside of the hospital, VBAC, unmedicated, water births, and models of care such as midwifery

According to a Harvard Law Review focused on reproductive justice:

"While a highly medicalized approach to birth is dominant in the United States, its prevalence is not explained by superior outcomes. In hospital births, between 27% and 41% of labors are induced, many without medical indication. Another 40-50% involve the use of synthetic oxytocin, or Pitocin, to speed up the labor process. About three quarters involve epidural pain medication, which numbs and immobilizes the birthing person from the waste down. Since 1965, cesarean rates have climbed from 4.5% to 31.9%. The rise in cesarean deliveries has not improved infant mortality, which remains higher in the United States than in any other comparably wealthy nation. Maternal mortality ranks fifty-fifth in the word, after Russia, and is climbing. Infant and maternal death rates for Black and indigenous people are two to five times those for white people."

### In comparison:

"Midwifery care results in different outcomes than the medical model. Home births and birth center births have cesarean rates of 5-6%. The rates of postpartum hemorrhage or severe tearing are lower than in hospitals. Neonatal intensive care unit admission is exceptionally low. Less than 5% require oxytocin augmentation or epidural anesthesia. Breastfeeding rates at six weeks are greater than 97%. While studies are inconsistent, the best available data indicate that neo-natal mortality at home or in a birth center is similar to that in hospitals. Maternal mortality is roughly the same. Midwife-led care in hospitals shows similarly strong outcomes. Satisfaction with the birthing experience is higher under midwifery care, which may improve mental health outcomes" 25.

This suggests that, though hospital births are the more typical form of delivery, they are not always superior.

We heard from one parent who traveled several hours—while in labor—to give birth at a CABC accredited birthing center in Nashville that had a partnership with a hospital. Some parents who desired certain birth options reported that cost and coverage prevented them from accessing these birth options. Having access to a CABC accredited birthing centers locally would create safer alternatives that don't require long travel to giving birth in Louisville—and could cut down on overly burdened providers. Expanding access and affordability of birth options, such as: births outside of the hospital, VBAC, unmedicated, water births, and models of care such as midwifery could similarly reduce Louisville providers' burden.

Vanderbilt Health Center—formally Baby + Co—is a potential model for the type of birth options that some parents requested that could be potentially replicated in Louisville. Vanderbilt Birth Center<sup>26</sup> reports that they are the region's only "out-of-hospital birth experience." It is a CABC accredited birth center, and is reportedly staffed almost entirely by certified nurse-midwives and offers a host of services that the mothers that we heard from requested. Such a center—partnered with a medical hospital—could offer birth options, such as: births outside of the hospital, VBAC, unmedicated, water births, and models of care such as midwifery to mothers who can safely pursue these options. Notably, a similarly accredited birthing center in nearby Jeffersonville, Indiana—Tree of Life Birth Center<sup>27</sup>. As indicated previously, strengthening partnerships between this center and area hospitals, making this birth center more affordable and accessible, or establishing a Louisville birthing center could address many of the concerns of mothers who wanted alternative birth options while also relieving the current stress on providers.

### 6. Increase support following delivery

Based on these reports, we recommend that providers and advocates ensure that breastfeeding support is available and encouraged and that communication is transparent so that parents who are breastfeeding or desire to breastfeed don't feel undermined by providers.

We also recommend that advocates and policymakers make counseling resources related to postpartum depression affordable and accessible to the mothers who need them. We also recommend that prenatal care providers incorporate conversations about postpartum depression into care before delivery, so that expecting parents are familiar with the potential for experiencing postpartum depression and opportunities for postpartum assistance and care.

Area hospitals currently lack standardized EMR-embedded assessments with post-natal counseling or postpartum support referrals. We recommend that area hospitals and birthing centers should use an evidence based assessment tool—such as the Edinburgh<sup>28</sup> post-natal screening tool—prior to hospital discharge and at the postpartum visit. Standardizing such a practice could help providers to initiate conversations with new parents about postpartum depression as well as postpartum-related assistance and care.

Area hospitals and referring agencies should also strengthen knowledge of, and connections to culturally concordant or sensitive mental health providers in the Louisville area, so that they can make such referrals when evidence-based assessments suggest that postpartum care may be needed.

The Maternal and Child Health team in the Center for Health Equity has a developed proposal for American Rescue Plan (ARP) funding that is aimed at establishing an evidence-based referral program for Black mothers. Should this program fail to be funded by ARP, maternal and child health advocates should seek out other sources of funding or implementation for this framework.

Additionally, the Norton Healthcare community-based doula program discussed previously offers some post-pregnancy support. This post-pregnancy support could be expanded or added to. We also heard from one mother who was involved in local efforts to provide mental health services and safe spaces for recent mothers suffering postpartum depression called "Mom friends," which was hosted by Play Cousins collective.

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